GOVERNMENT OF INDIA
HEALTH AND FAMILY WELFARE
LOK SABHA

UNSTARRED QUESTION NO:1067
ANSWERED ON:21.07.2017
Rare Diseases
Jaiswal Dr. Sanjay

Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

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(a) the estimated number of people suffering from rare disorders like thalassaemia, rare cancers, muscular dystrophy, auto immune diseases, etc. in the country;

(b) whether the Government has formulated any policy framework addressing the needs of people suffering from such disorders;

(c) if so, the details thereof; and

(d) if not, the reasons therefor along with the steps taken by the Government to ensure effective care to such patients?

Answer

ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND
FAMILY WELFARE
(SMT. ANUPRIYA PATEL)
(a): An expert group constituted by the Ministry of Health & Family Welfare in March 2016 suggested that amongst the estimated 7000 different rare diseases in the world, the Lysosomal storage diseases (LSDs) and the Inborn errors of metabolism (IEMs) are of immediate relevance in India. Currently, India doesn't have epidemiological data on rare diseases and consequently no comprehensive data on burden and prevalence of rare diseases and the associated morbidity and mortality.

(b) to (d): Yes. A National Policy for treatment of Rare Diseases in India has been formulated to progressively build India's capacity to respond comprehensively to rare diseases covering areas of: prevention, awareness generation, training of doctors, funding support for treatment on the parameters to be defined by a Central Technical cum Administrative Committee, promotion of research and development for drugs for treatment of rare diseases and diagnostics at affordable prices and measures for making the drugs for rare diseases more affordable, strengthening of laboratory networks, development of Centres of Excellence etc. On the whole, the Policy seeks to strike a balance between the interest of patients of rare diseases and health system sustainability. The Policy also recognises and delineates the role of various Ministries and departments in the area of rare diseases.